University of Chester

Department of Clinical Sciences and Nutrition

MSc in Obesity and Weight Management

Living with Multiple Sclerosis – exploring the effects of physical activity on quality of life.

Research Project

Module Code: XN7211

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Student Number: J24321

Submission Date: 31st August 2017

Literature Review Word Count: 4331

Research Article Word Count: 4383

Contents

Acknowledgements

I would like to thank Professor Lynne Kennedy for her help and advice throughout this research project.

I would also like to thank Dr Orla Flannery for her support throughout the Obesity and Weight Management MSc.

Finally, I would like to thank all of the participants who were involved in the interview process for their time and willingness to share their personal experiences.

Declaration

I declare that this work is original and has not been submitted previously for any degree qualification or other course. This research project is submitted as part of a Master's degree in Obesity and Weight Management.

Signed:

Date: 31st August 2017

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Abbreviations

ACSM	American College of Sports Medicine
BMI	Body Mass Index
CIS	Clinically Isolated Syndrome
CNS	Central Nervous System
DH	Department of Health
EDSS	Extended Disability Status Scale
FSS	Fatigue Severity Scale
MFIS	Modified Fatigue Impact Scale
MSIS	Multiple Sclerosis Impact Scale
MRI	Magnetic Resonance Imaging
MS	Multiple Sclerosis
NICE	National Institute of Health Care
NHS	National Health Service
pwMS	People with Multiple Sclerosis
PA	Physical Activity
PPMS	Primary Progressive Multiple Sclerosis
QoL	Quality of Life
RCT	Randomised Control trial
RRMS	Relapsing Remitting Multiple Sclerosis
SF-36	Short Form 36
SCT	Social Cognitive Theory
SPMS	Secondary Progressive Multiple Sclerosis
WHO	World Health Organisation

Abstract

The findings of this study suggest that organised health interventions play a significant role in helping decrease social isolation and improve quality of life to those living with Multiple Sclerosis. Multiple Sclerosis is one of the most common neurological diseases in Great Britain. It is a disease of unknown aetiology, unpredictable prognosis, and limited disease-modifying treatments. Recent research has suggested a link between childhood obesity and other environmental factors in multiple sclerosis susceptibility. Some people can experience little disability during their lifetime but 40% of patients require a wheel chair within 10 years of diagnosis. This has significant implications for the patients' quality of life and is a financial cost to society. This makes lifestyle behaviours, such as physical activity, an important part of the patients' rehabilitation. This paper has considered the benefits of physical activity to the general population and to those with Multiple Sclerosis. A qualitative study using face to face semi-structured interviews has been used on 12 people living with multiple sclerosis to investigate the barriers to exercise participation and perceived effects on quality of life.

The results show the importance of physical activity on a patient's quality of life providing symptom management, psychological, and social benefits. An integral role of the patients' health and well-being is the recommendation of exercise at disease on-set.

"To digest that information, diagnosis of a lifelong disease, with a lack of positivity or optimism must only add to the stress and anxiety".

Literature Review: Living with Multiple Sclerosis – exploring the effects of physical activity on quality of life.

Introduction

According to Weiler, Stamatakis and Blair (2010) inactivity has become one of the greatest health threats facing developed nations. Regular exercise and physical activity (PA) have wide-ranging benefits for physical and emotional well-being and has been well researched for the general population (American College of Sports Medicine, [ACSM] 2017; Woodcock, Franco, Orsini & Roberts, 2011). Inactivity is a risk factor in chronic diseases and is generally easy for most people to do something about (Booth, Roberts, & Laye, 2012; Jelinek, 2016). Epidemiological data obtained through longitudinal studies and controlled trials have associated increased PA with decreased risk of heart disease, stroke, type 2 diabetes, and high blood pressure (Adegbija, Hoy, & Wang, 2015; Myers, 2003). Exercise and PA, although different, do overlap on the beneficial effects they achieve on various health outcomes. Physical activity is defined as any bodily movement produced by skeletal muscles that requires energy expenditure and exercise is a type of PA that is planned and structured (Caspersen, Powell, & Christenson, 1985; World Health Organisation [WHO], 2017).

Quality of life (QoL) can be impaired in multiple sclerosis (MS) due to physical disability, fatigue, and depression. It is a chronic and disabling disease of the central nervous system (CNS). The precise etiology of MS remains unclear but evidence

confirming the benefits of PA and exercise in people with MS (pwMS) is growing. Recent research has shown magnetic resonance imaging (MRI) scans of the brain show less deterioration than those who are more aerobically fit (Ohio State University, 2010) and studies suggest that exercise could help with cognitive function by promoting nerve growth (Coote et al., 2014; National Multiple Sclerosis Society, 2015; Ohio State University, 2010; Paul et al., 2014). Exercise is becoming one of the key components highligted in the mangement of MS symptoms and also deceases the risk of secondary conditions e.g. type 2 diabetes (Backus et al., 2017; Paul et al., 2014). MS remains incurable and lifestyle changes, which were once classed as an “alternative” therapy, have now been shown to have a positive impact on QoL (Burgess, 2002).

This review has two main aims:

1. Understand the benefits of PA to the general population with a primary focus on those living with MS.
2. To gain a more in-depth understanding of the barriers and motivators to PA participation from the perspective of pwMS.

Background

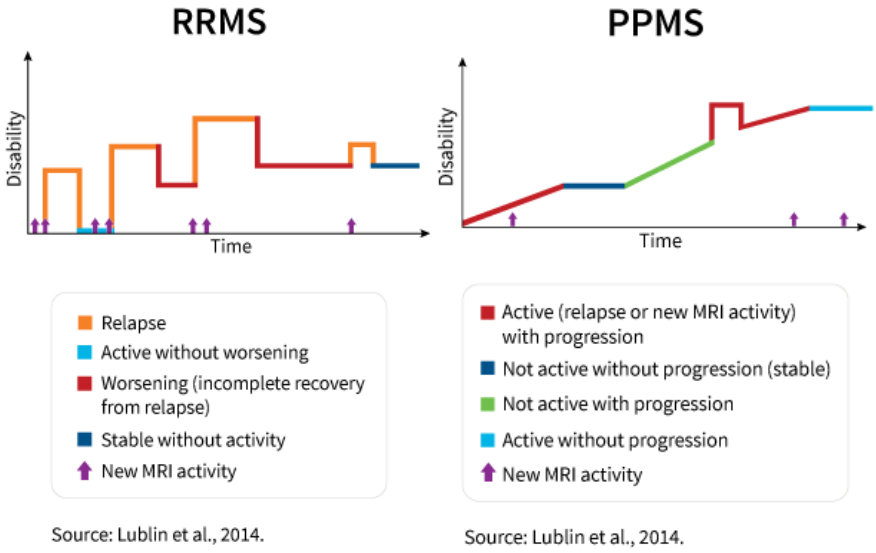
Multiple sclerosis is a neurological condition of unknown cause that is characterised by damage to the myelin sheath which, when healthy, protects the nerves of the CNS (Motl, McAuley, & Snook, 2005). Depending on the area of the CNS affected, MS can cause a range of symptoms: motor, sensory, including fatigue, pins and needles, balance, walking ability, and vision problems. The three main classifications of MS are relapsing remitting MS (RRMS), primary progressive (PPMS), and secondary progressive MS (SPMS). A definition of each type was established in 1996 and updated in 2013 when clinically isolated syndrome (CIS) was acknowledged as the first presentation of the disease (Lublin et al.,1996 & 2014) (Table 1.1). Most people, 85%, are diagnosed with the RRMS form that is characterised by intermittent periods of inflammation in the CNS (i.e. a relapse). Table 1.2 shows the disease progression of the three main types of MS.

Table 1.1. *Definition of each type of MS taken from Lublin et al., (2013)*

Type of MS	**Definition**
Relapsing-remitting MS (RRMS)	Clearly defined disease relapses with full recovery between relapse
Primary Progressive MS (PPMS)	Disease progression from the onset with occasional plateaus
Secondary Progressive MS (SPMS)	Initial RRMS followed by constant progression of the disease
Benign MS	Disease where patient sees no progression or relapse 15 years after onset
Clinically Isolated Syndrome (CIS)	First clinical presentation of the disease that shows characteristics of inflammatory demyelination that could be MS, but has yet to fulfill criteria of dissemination in time.

Table1.1. Description of Multiple Sclerosis type. From “Defining the clinical course of multiple sclerosis: the 2013 revisions”, F. Lublin, F. D., Reingold, S. C., Cohen, J. A., Cutter, G. R., Sørensen, P. S., Thompson, A. J., … Polman, 2014, *Neurology*, *83*(3).

Table 1.2. Graphs showing different types of MS



Source: Lublin et al., 2014.

Source: Lublin et al., 2014.

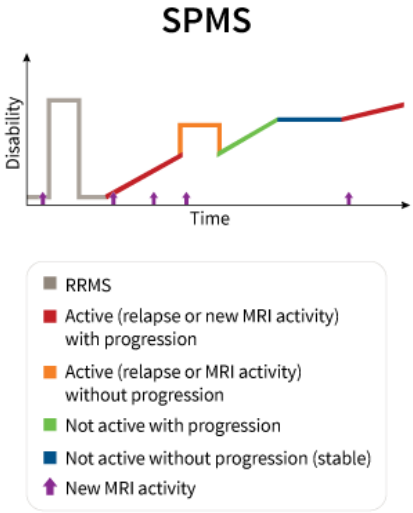


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Table1.2. Description of Multiple Sclerosis type. From “Defining the clinical course of multiple sclerosis: the 2013 revisions”, F. Lublin, F. D., Reingold, S. C., Cohen, J. A., Cutter, G. R., Sørensen, P. S., Thompson, A. J., … Polman, 2014, *Neurology*, *83*(3).

It is estimated that 2.3 million individuals are affected with MS worldwide with about 100 people newly diagnosed each week in the UK (MS Society, 2016). People are living longer into old age and an increasing number of them will have to cope with a disability such as MS. This is an enormous strain to the National Health Service [NHS] with the cost of emergency hospital admissions and treatment costing £43 million in 2014 (Thomas, Mynors, Simpson, Meade, & Bowen, 2015). This clearly points to areas where improvements in care are needed to prevent secondary complications of MS, reduce hospital admissions, and improve QoL in pwMS.

In a review by Ginfrancesco and Barcellos in 2016 both environmental and genetic factors were implicated in MS aetiology. This genetic susceptibility explains the clustering of MS seen in families, but lifestyle factors are also associated with the onset of the disease: exposure to tobacco smoke, low levels of vitamin D, salt intake and other dietary factors which can affect the immune function, and most recently, obesity (Ascherio & Munger,2016). It has been concluded that there is strong evidence supporting the role of childhood obesity in MS susceptibility and Ascherio and Munger have estimated that eliminating childhood obesity could prevent approximately 15% of MS cases. Other research has suggested that young adult obesity, rather than childhood, increases the risk of MS (Hedstrom, Olsson, & Alfredsson, 2016). The researchers observed a significant association ($p<0.001$) between adolescent obesity and early age of MS onset. Self-reported body mass index (BMI) was used for older particiapants (mean age 20) and silhouette images were used to assess the weight of children in this study. There are limitations to both these methods, where overweight individuals may have a more favourable perception of body silhouettes (Tehard, Van Liere, & Nougue, 2002), and BMI tends

to be underestimated (Gosse, 2014). However, the research into how obesity maybe another lifestyle factor that contributes to the development of MS is expanding (Mokry, 2016).

The disease is becoming more prevalent in the UK and worldwide (Hirst, Ingram, & Pickersgill, 2009; Kingwell, 2015). The improved detection of MS may explain some of the increase, but the recent change in disease incidence is likely to be the result of environmental factors (Correale, Farez, & Gaitán, 2017; Queen Mary University of London, 2016). Modifiable lifestyle factors, e.g. exercise and diet, can provide behavioural approaches for managing symptoms and QoL in MS and is a high priority for pwMS (Motl et al., 2017). The research by Motl and colleagues concluded pwMS wanted to know whether lifestyle modifications can impact on the course of the disease and stressed the importance of developing an agenda on healthy aging with MS through PA. The Multiple Sclerosis Society (2013) identified their top 10 research priorities and PA was included in this under “treatments that are effective to slow, stop or reverse the accumulation of disability associated with MS” and “treatments […] effective for fatigue in pwMS”. It has been suggested that PA has a potential to slow down the disease progression, improve QoL, and promote neurogenesis (Dalgas & Stenager, 2012; Vister et al, 2016). In a large recent cross-sectional study of 2312 pwMS factors associated with a better reported QoL where moderate to high PA, non-smoking, and a better diet (Jelinak et al , 2016). It was also noted that the taking of disease-modifying drugs showed lower measured QoL using validated physical and mental questionaires. It is important that pwMS are aware of how lifestyle factors may affect their progression rate or relaspse and are able to make informed decsions regarding their lifestyle choices.

Benefits of Physical Activity on Health

The current recommended guideline for adults is to engage in at least 150 minutes of moderate-intensity exercise each week and incorporate muscle strengthening exercises twice a week (ACSM, 2017; Department of Health [DH] 2010) (Table 1.3). Expert panels, including ACSM and the Centre for Disease Control and Prevention, reinforced scientific evidence on the benefits of PA and clarified the amount and intensity required to improve health and decrease premature mortality. Even with the evidence of the health benefits widely available, 26% of adults living in the UK fail to reach 30 minutes of PA per week and are classed as inactive (NHS Digital, 2017).

Table 1.3. Modified from ACSM's (2017,) Guidelines for Exercise Testing and Prescription

	Aerobic Exercise Evidence -Based Recommendations	**Volume of Resistance Exercise (sets and repetitions) Recommendations**
FREQUENCY	≥5 days a week moderate exercise ≥3 days a week of vigorous exercise	2-3 days a week – with at least 48 hours separating sessions
INTENSITY	Moderate and/or vigorous Light-to-moderate for deconditioned individuals	2-4 sets 8-12 repetitions
TIME	30-60 minutes of purposeful moderate activity Or 20-60 of vigorous exercise	*All individuals should perform resistance training using correct technique employing controlled movements through full ROM - therefore no time is given*
TYPE	Regular, purposeful exercise that involves major muscle groups	Multi and single-joint targeting agonist and antagonist muscle groups

Table 1.3. Table showing exercise guidelines for exercise testing and prescription. From *ASCM's Guidelines for Exercise Testing and Prescription (10th ed., p.162 & p.168*), American College of Sports Medicine, 2017, Wolters Kluwer.

Myers (2003) found PA has a powerful influence on many chronic diseases and many studies have concluded aerobic capacity has an inverse relationship with risk

of premature death (Blair et al., 1995; Garber, 2011; Williams, 2013). Enhancing muscular fitness is associated with a lower risk of developing physical function limitations, improved body composition, and insulin sensitivity (ACSM, 2017). Recent research has suggested that resistance training is as effective as aerobic training in the management of type 2 diabetes (Yang, Scott, Mao, Tang & Farmer, 2014). This systematic review used high quality randomised control trial's (RCT), but all were of short duration (medium 4 months). The results may not translate to long-term benefit in diabetic complications but as highlighted by Thomas, Elliot, Naughton (2006), all types of exercise will achieve benefits if maintained. Resistance training can also improve bone mineral density, which may help prevent osteoporosis and even reduce disability in individuals with osteoarthritis (Garber et al., 2011; Messier et al., 2009). Evidence is also emerging to suggest that exercise may slow the progression of age-related cognitive function by strengthening the connections in the CNS (Hardman & Stensel, 2009; Kirk-Sanchez & McGough, 2013). Kirk-Sanchez and McGoughs' review did include some studies on rats and mice, which may not predict human responses, but evidence was observed that exercise helped neurons to grow and improve brain health. In another study, which again used rats, the researchers analysed the effects of aerobic training compared with the resistance training – where the rats climbed ladders using weighted packs - interval training - alternating short bouts intense anaerobic exercise with recovery periods, and a control sedentary group. New neurons were observed most in the rats in the aerobic group, providing preliminary evidence that engaging in sustained aerobic exercise promotes neurogenesis (Nokia, et al, 2016). This research was carried out on male rats and there is no firm evidence yet that the same kind of effect will happen in humans but does show compelling evidence that exercise may help achieve a

healthier old age and protect against diseases such as Alzheimer's. Exercise therapy can be one means of decreasing disability and increasing QoL in the general population and for those living with a chronic illness.

Benefits of Physical Activity for People with Multiple Sclerosis

The benefits of exercise in the general population are well established and numerous studies have been conducted over the last few decades on people with MS.
Much of the research on exercise on pwMS has limitations: MS is a highly heterogeneous disease, making comparisons to a control group difficult, many of the studies have low participation numbers, type of MS may not be defined, and it is difficult to blind participants in rehabilitation interventions. Ritchie Russell, a Professor of Neurology at Oxford, conducted a study on 21 people living with MS where they completed short bursts of intense exercise including press-ups and weight lifting exercises (Russell, 1976). He reported results that he felt arrested disease progression from this interval style therapy. This research was completed in 1974, when there was a strong medical opinion that pwMS should avoid exercise due to raising the body's core temperature – a condition called Uthoff's phenomenon – which was thought to exacerbate MS symptoms (Jelinek, 2016). Research has produced evidence showing that exercise is an integral component of disease management in those with mild to moderate disability (Brown & Kraft, 2005; Doring, Pfueller, Friedmann & Dorr, 2011; Sunderland & Andersen, 2001). Exercise and PA have now been proven to be well tolerated by pwMS and can help stop secondary chronic diseases (Dalgas & Strenager, 2012). However, even with evidence now emerging on how PA can impact on symptom management for those living with MS, recommended guidelines about the level of participation are not well publicised.

Table 1.4 shows the ACSM (2017) recommended frequency, intensity, time, and type for people living with mild to moderate MS. These are similar to the Canadian PA guidelines (Appendix A) which are recommended on the National Multiple Sclerosis Society website but not on the UK MS Society website (National Multiple Sclerosis Society, 2017).

Table 1.4 – Guidelines for pwMS Exercise Testing and Prescription

	Aerobic Exercise Evidence -Based Recommendations	**Volume of Resistance Exercise (sets and repetitions) Recommendations**	**Flexibility**
FREQUENCY	2-5 days a week	2 days a week	5-7 days a week 1-2 times a day
INTENSITY	40% - 70% VO_2R or HRR; RPE 12-15	60-80% 1RM	Point of mild discomfort
TIME	Increase time to a minimum of 10 minutes. Progress to 30-60 mins as tolerated	Begin with 1 set building to 2 sets 10-15 repetitions	Hold for 30-60s 2-4 repetitions
TYPE	Rhythmic activities using major muscle groups	Multi and single-joint, using machines, free weight, body weight and bands	Static stretching

Table 1.4. Table showing exercise guidelines for people with Multiple Sclerosis. From *ASCM's Guidelines for Exercise Testing and* Prescription (10th ed., p.343), American College of Sports Medicine, 2017, Wolters Kluwer.

Whether exercise participation can reverse MS or have an impact on disease progression is more difficult to study because of the unpredictable and varied course from one individual to another (Burgess, 2002). Dalgas and colleagues completed a series of studies addressing the relationship between PA, disease progression, and QoL (Andreasen, Dalgas & Strenger, 2011; Dalgas et al., 2010; Dalgas & Strenger 2008; 2012; 2014). Andreasen, Dalgas & Strenger's review in 2011 examined the effect of exercise therapy on fatigue, a common barrier to exercise participation for pwMS (Ploughman, 2015). A variety of exercise interventions had been used in the original 23 papers, but fatigue was only the primary outcome measure in eleven of those studies. The authors did not state how these studies were analysed, but did

conclude that exercise therapy could induce positive effects on MS fatigue. A limitation is that different measures were used to analyse the fatigue in the 23 papers: MFIS, FSS/4-5, Chalders Fatigue Scale, and in-depth interviews (Appendix B – Characteristics of MS Impact Scales for Measuring QoL and Fatigue). For stronger results to be drawn there needs to be limited variance in baseline fatigue levels and a reduction in the fatigue analysis methods. Not all fatigue impact scales correlate well with each other and the Chalders Fatigue Scale was created for chronic fatigue syndrome patients and is not specific to MS (Braley & Chervin 2010). Use of these scales may not always be necessary; the important factor is the patient endorses the symptom and can self-evaluate the treatment response. Large-scale RCT's to fully demonstrate the effectiveness PA on fatigue in the MS population are lacking but literature strongly suggests a correlation.

There was strong evidence found by Patti et al. (2002, 2003) in a high quality RCT with 111 participants with either PPMS or SPMS who reported reduced functional limitations, including fatigue, after a comprehensive outpatient treatment. Subjects were allocated to a control group of home exercise or a treatment group of an outpatient treatment. The treatment lasted 12 weeks and included physiotherapy, exercise, speech, and occupational therapy. At 12 weeks, the treatment group saw a significant difference in various areas ($p<0.001$): fatigue, social function, motor and cognitive function, and depression. These outcomes were measured using the validated SF-36 questionnaire (Appendix B). A limitation of this study was that the self-executed exercise home programme was not clearly described and the potential cost of replicating the outpatient treatment therapy will make this intervention limited. Building on this research, Dalgas & Strenger (2012) have suggested that exercise

may have a neuroprotective effect which could modify the course of pwMS in addition to improving the symptoms. The authors completed a literature review and concluded that exercise could influence the trajectory of MS. The inclusion of MRI scans as an outcome measure in future studies could help prove the effect of exercise on neurotrophic factors as observed by Nokia et al, (2016) in their study using rats. Similar research by Grover et al. (2015) found that low levels of PA corresponded with a higher disease burden (increase in T2 lesions and relapse rates) in pediatric MS patients using MRI brain analysis.

Another series of studies was completed by Motl and colleagues (Motl, 2008; Motl & Gosney, 2008; Motl et al., 2008; Motl & McAuley, 2011; Motl & Pillutti, 2012), addressing the relationship between PA, symptoms, and disability in pwMS. One longitudinal study lasting between 3 and 5 years researched the relationship between self-reported PA levels and the worsening of symptoms (Motl et al., 2008). The study showed that the worsening of symptoms was positively associated (p=0.04) with lower levels of activity in 51 participants with varying MS classifications. Due to the limited details on the methodology in this study it is difficult to conclude that a reduction in PA is a behavioral correlate of MS or the cause of disability progression. In 2011 Motl and McAuley published two longitudinal studies testing the theory that a change in PA levels would be inversely associated with disability progression. The first study was on 292 MS patients who wore an accelerometer for 7 days as a measure of their PA at baseline and then again at 6 months. Panel analysis was used to show that a change in PA was associated with a change in disability progression (path coefficient=-0.09, p=0.025). Again, it was concluded that a reduction in PA correlates to disability progression. The study had

a high number of participants, but a limitation was all subjects had a low level of disability (the inclusion criteria was walking without assistance), and the research study, was short taking place over 6 months with no follow-up assessment.

Two high quality RCT's (Dalgas et al., 2010; Oken et al., 2004) reported improvements on QoL and fatigue in a range of different intervention types including yoga, aerobic training, and progressive resistance exercise. Due to the nature of the interventions, neither the participants nor the therapists could be blinded. Oken et al. (2004) compared multiple exercise interventions versus a single control group and found participants in the exercise interventions self-reported improvements using the short form health survey (SF-36). The SF-36 does have limitations in its use if not administered by a therapist, where an explanation can be given (Hobart, Freeman, Lamping, Fitzpatrick, & Thompson, 2001). A strength of the studies is that both Dalgas and Oken completed the intervention with an interview analysis where participants completed the health survey. Oken et al. (2004) had an overall drop-out rate of only 17%, which was due to difficulties attending so are unlikely to be related to treatment allocation. Type of MS was not identified which limits the applicability of the results for future interventions. Dalgas et al (2010) completed their resistance training RCT on 38 candidates with RRMS reporting small but significant results to muscle strength, functional capacity, fatigue, mood and QoL. Quality of life improved by 3.5 (95% CI 1.4–5.7), measured using the SF-36. This trial included a follow-up phase at 12-weeks which showed no change in fatigue levels post intervention or follow-up measurement. Importantly though, other benefits of QoL disappeared once the training stopped suggesting interventions should focus on behaviour change to see long-term benefits. Pilutti, Dlugonski, Sandroff, Klaren, and Motl

(2014) found supplementing an intervention using social cognitive theory (SCT) and incorporating video coaching demonstrated moderate to large improvements in PA and this change was maintained for 12 weeks post-intervention. Table 1.5 presents a summary of included RCT's.

Table 1.5. Summary of Randomised Control Trials exploring benefits of PA participation

Study	Intervention	Recruitment & Eligibility	Participants Characteristics	Withdrawals	Key findings
Dalgas et al., 2010	**Treatment** 12-week resistance training twice a week sets & repetitions progressing through weeks **Control** Advised to continue normal PA for 12-weeks then were offered treatment	MS Clinic Aarhus University Hospital between May & October 2006 RRMS EDSS between 3 and 5.5 Age >18	**Treatment** *n*=19 **Control** *n*=19	4 from exercise 3 from control	SF-36 Significant improvement on FSS score Fatigued improved measured on MFI-20
Oken et al., 2004	Yoga Vs aerobic exercise 26-week intervention **Yoga** – 90 minutes once per week plus home booklet **Aerobic** – light to moderate cycling until fatigued once per week plus home bike **Control** Wait list control	Local newspaper and MS Centre EDSS ≤6.0 Presence of a medical condition that may impair cognition	**Yoga** Mean age 49 Female 91% *n*=26 **Aerobic** Mean Age 49 Female 87% *n*=21 **Control** Mean age 48 Female 100% *n*=22	4 from yoga 6 from aerobic 2 from control	Significant improvement from both Yoga and Aerobic exercise measured on SF-36, MFI, POMS fatigue sub-scale MSFC including 25-foot walk

Study	Intervention	Recruitment & Eligibility	Participants Characteristics	Withdrawals	Key findings
Patti et al., 2002 & 2003	**Treatment** 6-week outpatient rehabilitation including: physiotherapy, exercise, speech, and occupational therapy + 6-week home exercise **Control** 12-weeks home exercise	Admitted to the Centro Sclerosi Multipla of the Policlinico of the University of Catania Italy between January 1998 and December 1998 PPMS or SPMS EDSS between 4.0 & 8.0 Age between 18 & 65	**Treatment** 25-60 years Female 58% *n*=58 **Control** 30-57 years Female 57% *n*=53	4 from treatment 1 from control	Significant difference in treatment $p<0.001$ improvement measured on SF-36 - fatigue, social function, motor and cognitive function, and depression
Pilutti, Dlugonski, Sandroff, Klaren & Motl, 2014	**Treatment** 6-month Behavioural SCT Pedometer Webcam **Control** Wait list	North American research Committee on multiple Sclerosis database 18-64 years Diagnosis of MS Ability to walk with or without aid Internet access **Exclusion Criteria** Participates ≥30 minutes PA	**Treatment** Mean age 48.4 Female 73% *n*=41 **Control** Mean age 49.5 Female 78% *n*=41	4 from treatment 2 from control	Significant difference $p=0.001$ (FFS) in fatigue $p=0.006$ (HADS) depression and anxiety no significant difference in quality of life (MSIS-29)

Behaviour Change

Understanding behaviour modification, including motivators and barriers to exercise adherence, appears to be paramount in improving the health of the nation and for those living with MS. Participation in PA in individuals diagnosed with MS is generally low, making this population particularly vulnerable to a range of secondary conditions associated with physical inactivity (Balto et al, 2016; Motl, McAuley & Snook, 2005; Currie, Knox, Glazebrook, & Brawley, 2009). In PA adherence, the person must value the improvements that will be seen, e.g. cardiovascular health enhancement for weight loss and lower fatigue levels for pwMS. Many recent studies have used SCT for promoting health behaviours in both the general population and among diseased individuals. In a large observational study, using SCT methodology, of 2000 obese participants it was found that the dropout of participants was associated with unrealistically high weight loss expectations (Melchionda et al. 2003; Grave et al. 2005). Of further interest from this study is that long-term weight maintenance (over 3 years) was observed most in those patients satisfied with their initial weight loss at the short-term assessment (Grave et al. 2005). This suggests that goals should be realistic and set at the beginning of the intervention to help achieve retention and long-term results. Motl and colleagues in their series of studies were specifically interested in PA engagement for pwMS. A strength of their work is the use of SCT which has been well-researched and is regarded as a key theory for explaining PA behaviour in other populations. McAuley & Motl et al. (2007) conducted a 3-month RCT of 26 patients assigned to either a standard care programme or efficiency enhancement exercise group. The efficacy enhancement exercise group involved lectures including topics on exercise self-

efficacy, goal-setting, barriers, and social support. They also formed “buddy groups”. The control group were involved in workgroups discussing general health-related topics. Both groups conducted 3-months of exercise at separate leisure centres. After the 3 months, persons in the efficacy enhancement exercise condition reported to working harder and having higher levels of well-being. These findings were not significant at the 3-month stage but the results did show that the efficiency enhancement group were attending more training sessions and training for longer. A follow-up at 6-months would help assess the capability of SCT on pwMS. Non-face-to-face interventions are seen as an alternative, cheaper method of promoting health. Motl, Dlugonski, Wojcicki, McAuley, & Mohr (2011) assigned 54 pwMS to either an internet intervention group or a waitlist control and reported a statistically significant (p=0.01) increase in PA over time compared with the control. In their latest research (Motl, Kinnett-Hopkins & Ensari, 2017) found results that indicated goal-setting and self-efficacy are of importance when designing interventions for persons with MS. This was a larger study than the previous, involving 551 pwMS but, like other larger studies, self-reported measures of PA were used.

Barriers to exercise have been well researched in the general population with factors relating to lack of time and cost identified as some of the key barriers (Mailey, Huberty, Dinkel & Mcauley, 2014). Cultural, social, socio economic, and environmental factors have also been identified as common trends that can affect PA participation. For people with MS, barriers to PA also include access to adaptive exercise equipment, information about the benefits, fatigue, emotional and psychological factors, transportation, and perceptions about individuals with disabilities (Brown, Kitchen & Nicholl, 2012).

Discussion

In the absence of a cure for MS, lifestyle changes including PA and exercise, can have a beneficial effect on symptom management and improve a person's overall health and well-being. Despite this growing evidence research has confirmed that there is a lower level of participation than in the general public (Stennett, De Souza & Norris, 2017). It is important to engage pwMS as early as possible to minimise symptom progression (Dalgas & Stenager, 2012). Research has established the efficacy of appropriate exercise in counteracting functional decline and cognitive impairment, as well as depression and anxiety (Cormie, Nowak, Chambers, Galvão, & Newton, 2015). The passage of information along the CNS is damaged for pwMS but the potential role of exercise to promote nerve growth, increase myelination, and QoL should be given a stronger consideration. The rehabilitative effect of exercise interventions in neuro-oncology is important and outcome measures of MRI with a suitable physical assessment e.g. the six-minute walk test can assess disease activity and progression. Research into this area, along with brain inflammation and the effects of diet are important areas for pwMS and other degenerative diseases (Valdearcos, 2017). There have been improvements in the standard of research: studies now use a control group and the type of MS is identified. Limitations are that the studies are generally short, with the RCTs mentioned in this report ranging from 12-24 weeks. Exercise may have the greatest improvement on QoL and progression if started early in the disease so studies need to acknowledge the time since diagnosis of participants.

The evidence-base relating to the benefits of PA may be limited until the use of MRI scans or evoked potential tests which measure the speed of electrical conduction along the CNS as an outcome measure are commonly used. Current measurement of exercise interventions will always be limited when a range of questionnaires are used. The SF-36 is classed as the gold-standard of measurement of health status but even that has some limitations and should be supplemented with other physical measurements (Freeman, Hobart, Langdon, & Thompson, 2000). Engaging in PA produces positive health outcomes and this knowledge should be used to support and motivate pwMS to overcome perceived and actual barriers e.g. provide transport for future interventions.

Conclusion

The systematic reviews and RCT's have demonstrated PA is safe and is essential for overall wellbeing for pwMS (Dalgas et al., 2010; Motl & Gosney, 2008; Pilutti, Dlugonski, Sandroff, Balaert, & Motl 2014). The current research is limited, for the most part, to pwMS who suffer from a mild to moderate disability. The effects of exercise on fatigue were mixed in the systematic reviews, mainly due to the studies using non-fatigued participants (Andreasen, Dalgas & Strenger, 2011; Motl & Gosney, 2008). Progressive resistance training was found to improve walking ability and QoL and could be tolerated by those pwMS who are sensitive to heat (Dalgas, Strenager & Ingemann-Hansen, 2008). For those at an earlier stage of disease progression, with less disability, aerobic exercise has been shown to reduce depression, improve oxygen uptake, and may have a neuroprotective effect (Dalgas et al, 2010; Oken et al. 2004). Interestingly, even with this evidence, pwMS are not being recommended exercise as a therapy by healthcare professionals (Learmonth et al., 2016). Learmonth and colleagues found that pwMS wanted to be provided with guidance and resources on the merits of PA from their healthcare professional e.g. a neurologist.

Multiple sclerosis guidance from the National Institute of Health Care Excellence (NICE, 2014) recommends that pwMS are encouraged to exercise and accumulating evidence supports a positive relationship between PA and health outcomes. Burgess, an MS specialist nurse, wrote a book on the theory and practice of working with MS patients for nurses in 2002. She explained that pwMS should be encouraged to pursue some form of exercise and used Petajan et al. (1996) study to

show that exercise does not lead to worsening of mobility and can infact have a positive impact on QoL. Twenty years later, the role of exercise for pwMS is well established as a safe and effective therapy for those with mild to moderate disability, but is not automatically recommended at diagnosis. Health professionals should consider focusing on PA behaviour as a method of improving QoL and limiting secondary conditions. A key barrier to participation is MS fatigue, which can be controlled through exercise (Ploughman, 2015). Considering the long-standing evidence in favour of PA for pwMS, it is surprising health professionals do not appear to recommend it for improving QoL.

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Appendices

Appendix A

Canadian Physical Activity Guidelines

FOR ADULTS WITH MULTIPLE SCLEROSIS

Guidelines

To achieve important fitness benefits, adults aged 18-64 years with multiple sclerosis who have mild to moderate disability need **at least:**

- **30 minutes of moderate intensity aerobic activity, 2 times per week,**

AND

- **Strength training exercises for major muscle groups, 2 times per week.**

Meeting these guidelines may also reduce fatigue, improve mobility and enhance elements of health-related quality of life.

Who are the Guidelines for?

- These guidelines are appropriate for adults (aged 18-64 years) with minimal to moderate disability resulting from either relapsing remitting or progressive forms of multiple sclerosis

Getting Started

- You may wish to speak to a health professional to find out what types and amounts of physical activity are appropriate for you.
- A health professional might include a doctor, a physiotherapist, or a qualified exercise professional.
- If you are are physically inactive , activities performed at a lower intensity, frequency, and duration than recommended may bring some benefit.
- Gradually increase duration, frequency, and intensity as a progression towards meeting the guidelines.

Now is the time. Walk, run, or wheel, and embrace life.

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MS SP

PARTICIPACTION

Canadian Physical Activity Guidelines

FOR ADULTS WITH MULTIPLE SCLEROSIS

HERE IS WHAT IS RECOMMENDED

	Aerobic Activity	Strength Training Activity
How often?	Two times per week	Two times per week
	• Aerobic and strength training activities can be done on the same day • Rest your muscles for at least one day between strength training sessions	
How much?	Gradually increase your activity so that you are doing at least 30 minutes of aerobic activity during each workout session.	Repetitions are the number of times you lift and lower a weight. Try to do 10-15 repetitions of each exercise. This counts as 1 set. Gradually work up to doing 2 sets of 10-15 repetitions of each exercise.
How hard?	These activities should be performed at a moderate intensity. Moderate-intensity physical activity is usually a 5 or 6 on a scale of 10, and causes your heart rate to go up. As a general rule if you're doing moderate-intensity activity you can talk, but not sing a song, during the activity.	Pick a resistance (free weights, cable pulleys, bands, etc.) heavy enough that you can barely, but safely, finish 10-15 repetitions of the last set. Be sure to rest for 1-2 minutes between each set and exercise.
How to?	Some options for activity include: Aerobic activities • Upper Body Exercises: arm cycling • Lower Body Exercises: walking, leg cycling • Combined Upper and Lower body exercises: elliptical trainer	Strength training activities for the upper and lower body • Weight machines • Free weights • Cable pulleys
	Other types of exercise that may bring benefits • Elastic resistance bands • Aquatic exercise • Calisthenics	

Appendix B

Characteristic of Impact Scales for Measuring Fatigue and Quality of Life Questionnaires

MEASURE	DESCRIPTION	CHARACTERISTICS
Multiple Sclerosis Impact Scale MSIS-29	The MSIS has 29 items, 20 of which address the physical impact of MS and nine assess the psychological impact. Participants are asked to rate how much MS has impacted on their ability to do certain tasks on a five-point scale ranging from 'not at all' to 'extremely'. *Used to measure QoL in a range of studies.*	The MSIS was the first MS-specific measure and was developed incorporating items generated from patient interviews. It has been tested on people with MS and the reliability and validity found to be good.
Short Form 36 SF-36	The Short Form-36 was derived from the General Health Survey of the Medical Outcomes Study by Stewart and colleagues (1988).	Patients can complete with little or no help from an interviewer. Takes approximately 10 minutes to complete. generates subscale scores for physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role-limitations due to emotional problems, and mental health
Modified Fatigue Impact Scale MFIS	This is a modified version of the 40-item fatigue impact scale (FIS) used to assess fatigue on QoL – it is abbreviated to a 21-item. It is based on items derived from interviews with MS patients concerning how fatigue impacts their lives. *White et al, 2004; Dalgas et al, 2010; Plow et al, 2009, McCullagh et al, 2009; Roehrs & Karst, 2004; Rasova et al, 2006; Rampello et al, 2007, Oken et al, 2004; Schulzetal et al, 2004*	The MFIS is a structured, self-report questionnaire that the patient can generally complete with little or no intervention from an interviewer. It takes only a couple of minutes to complete. The score is the sum of the 21 points. Limitations in interpreting the scores can lead to misinterpretation.
Fatigue Severity Scale FSS	The FSS was designed for MS patients and for patients with chronic fatigue syndrome. It consists of nine statements which can be answered on a 7-point scale. 1=strongly disagree with the statement to 7=strongly agree with the statement. *Gutierrez et al, 2005; Surakka et al, 2004; Petajanetal et al, 1996; Mostert & Kesselring, 2002; Kileff et al, 2005; Van den Berg et al, 2006; Newman et al, 2007; Geddes et al, 2009; Cakt et al, 2010*	The FSS is a self-administered questionnaire investigating the severity of fatigue in different situations during the past week. The final score represents the mean value of the 9 items.
CHALDERS FATIGUE SCALE	Self-administered questionnaire for measuring the extent and severity of fatigue. The questionnaire has been modified to 11-items. Each of the 11 items are answered on a 4-point scale: 'Better than usual', 'No worse than usual', 'Worse than usual' and 'Much worse than usual'. *Fragoso et al, 2008; Broach & Dattilo, 2001*	Chalder Fatigue Scale is one of the few who distinguish between mental and physical fatigue The scores are summed and a higher score indicates more severe fatigue.
INTERVIEWS	Qualitative study using semi structured interviews *Dodd et al, 2006; Smith et al, 2009*	Allows for in-depth feeling of patient to emerge but can be difficult to show reliability especially if different interviewers are used. Results are subjective.

Project Report

Living with Multiple Sclerosis – a qualitative study on the effects of physical activity on quality of life.

Rationale for Journal choice:

Multiple Sclerosis Journal (MSJ): Is a peer-reviewed international journal that focuses on all aspects of multiple sclerosis. This qualitative study aims to provide insight into the barriers and the effects of exercise participation on quality of life for those living with multiple sclerosis and maybe of interest to health professionals working in this field.

Abstract

Objective: To examine the effect of exercise on quality of life and investigate the perceived barriers to exercise participation.

Methods: A qualitative study using semi-structured one-to-one interviews on 12 participants with multiple sclerosis.

Results: Five qualitative themes were identified: environmental, personal, knowledge, quality of life, and taking control. Participants felt that discussing the benefits of physical activity engagement with a health professional and addressing problems such as transport would be helpful strategies for exercise engagement. All participants perceived that physical activity helped with quality of life.

Conclusions: These findings indicate that exercise therapy is beneficial to quality of life and that physical activity should be promoted by the neurologist at diagnosis.

Background and Introduction

The cause of MS remains unknown, but it is likely that a combination of genetic and environmental influences are involved in the aetiology of the disease. It is an illness of the central nervous system (CNS) characterised by scars in the myelin sheath that protects the nerves and facilitates conduction of nerve impulses. The damaged myelin forms scar tissue (sclerosis) and is affected along various areas in the CNS (multiple) (Scolding, 2012). Depending on the area of the CNS affected, MS can cause a range of symptoms: motor, sensory, fatigue, pins and needles, balance, walking ability, and vision problems. The number of years it takes to progress through the disability scale (Table 2.2) is highly variable but it is suggested that 40% of pwMS will need to use a wheelchair within 10 years of diagnosis. Many patients with MS report a family history demonstrating a significant genetic basis for MS susceptibility. Researchers have found 110 genes that may make an individual more prone to the onset of MS, but without exposure to certain environmental factors these may never be triggered (Scolding, 2012). The environmental factors most associated with the onset of the disease are: vitamin D deficiency (Alharbi, 2015), smoking (Wingerchuk, 2012), trauma, exposure to Epstein Barr virus (Scolding, 2012), and most recently obesity (Mokry, 2016). Other factors that may influence the course of the disease include: saturated fat, diary intake, and inactivity (Riccio,& Rossano, 2015; Swank & Goodwin, 2003).

Research is expanding rapidly in to the effects of gut bacteria and how this can cause inflammation of the central nervous system and trigger several neurological diseases including MS (Galland, 2014; Yarandi, Peterson, Treisman, Moran, &

Pasricha, 2016). Most research has been completed using rats but it has been suggested that gut microbiota can be changed through a combination of diet and exercise to control inflammation in the CNS (Jelinek, 2016). This makes exercise and diet interventions, which can have a positive consequence on the brain, an important area in rehabilitation for pwMS (Haghikia et al., 2015). This links in with the National Health Service [NHS] 5 year forward plan (NHS, 2015). This strategy highlights that prevention, and giving patients greater control of their own care, is key to making the NHS more sustainable. Multiple Sclerosis is still classed as an incurable disease, but most of the environmental factors responsible for the cause and progression of the disease are modifiable. This study aims to gain an insight into how PA can help improve quality of life (QoL) and explore barriers to participation in exercise.

Methods

Qualitative Approach

A qualitative approach using interviews was considered appropriate to undertake for this research. This method is applicable when wanting to explore the perspectives of the participant (Green & Thorogood, 2011). It therefore allows for greater capacity to gain more understanding on an individual's experience of MS and their feelings as to whether exercise has been a benefit. Qualitative research is sometimes referred to as "naturalistic" as it engages with words rather than numbers and the output of the data being studied is kept close to their natural state (Green & Thorogood, 2011, p.22; Hewitt-Taylor, 2011, p.13). Studies exploring the experiences of people with MS are therefore examining the phenomenology of pwMS, which acknowledges there is no single or 'correct' version of the truth, making, naturalism well suited for this study.

Participants and recruitment

Participants were invited to take part in face-to-face interviews to explore perceived effects of PA on QoL, including disease progression. Recruitment was through two means, mainly through attendance at the MS Society York branch and the East Riding MS activity session. Potential candidates were approached, asked if they were interested in participating in the study, and then provided with an information sheet with the researcher's contact details (Appendix A). The York Society also has a Facebook page with 100 members and an advertisement highlighting the opportunity to take part in a research project was placed there. The inclusion criteria were as follows: 1) ≥ 18 years of age; 2) a confirmed clinical diagnosis of one of the 5 types of MS; 3) ability to meet for face-to-face interview.

Ethical approval for this study was granted from the University of Chester Ethics Committee on 14th June 2017 (Appendix B). Consent forms (Appendix C) were signed by all participants in advance of the interviews. They were advised that they could withdraw from the study at any time without prejudice. Interviews were audio recorded with the participant's consent.

Sample Size

A total of eleven face-to-face interviews were conducted with individuals plus one phone interview. A target of 8-10 interviews was set originally with the addition of a small focus group if required. This is a feasible sample size to generate sufficient data to reach saturation and also feasible within the required timescale (Guest, Greg, Bunce, Arwen & Johnson, 2006). Similar qualatitive research studies have used 12 face-to-face interviews and allows the researcher to generate a subjective understanding of how and why people act in certain ways.

The aim was to capture experiences from pwMS who had a range of activity levels and a range of disease type. There was a possibility that participants would not know their type of MS or the correct terminology, therefore a description was available of each type to help identify the course of MS (Appendix D). This was only used in one instance. Table 2.1 provides a summary of participants.

Table 2.1. Participant Demographics

Participant Number	Age Category	Gender	MS Type	MS Abbreviation	Activity Level	Time since Diagnosis
1	40-49	F	Primary Progressive MS	PPMS	HIGH	5 months
2	60-69	M	Primary Progressive MS	PPMS	LOW	10 years
3	30-39	F	Relapsing-remitting MS	RRMS	LOW	6 years
4	50-59	F	Secondary Progressive MS	SPMS	MED	14 years
5	50-59	F	Secondary Progressive MS	SPMS	LOW	4 years
6	60-69	F	Primary Progressive MS	PPMS	LOW	10 years
7	20-29	M	Relapsing-remitting MS	RRMS	HIGH	2 months
8	50-59	F	Benign	Benign	MED	2 months (RRMS 15 years)
9	30-39	F	Relapsing-remitting MS	RRMS	LOW	12 years
10	50-59	F	Relapsing-remitting MS	RRMS	HIGH	16 years
11	40-49	F	Relapsing-remitting MS	RRMS	LOW	4 years
12	20-29	F	Clinically Isolated Syndrome	CIS	LOW	15 months

Study Design

A qualitative research design was adopted to explore the subjective experiences of pwMS who engaged in PA. Semi-structured face-to-face interviews were selected, which ensured important information was asked but allowed the informant to report their own thoughts and feelings. Purposeful sampling was not required as a range of MS type was achieved (Table 2.1). Interviews were conducted at a convenient, accessible site chosen by the participant, which allowed for participants who became fatigued to take short breaks. This is critical for people living with MS.

The interviews began with an assessment of the impact of MS in the last two weeks using the Multiple Sclerosis Impact Scale (MSIS-29) (Appendix E). This is a valuable outcome measure used in intervention studies, and was used in this research to evaluate the physical impact of MS on daily life and the effect of any exercise completed. It is a 29-item questionnaire and has been found to be a valid and reliable measure of disease impact (McGuigan, & Hutchinson, 2004). The Expanded Disability Status Scale (EDSS, Table 2.2) is commonly used to quantify disability, but was not judged to be beneficial for this study to measure QoL. It was given a score of 5.6/10 from pwMS on its usefulness to measure impact of the disease on their day-today life (Advances in Clinical Neuroscience and Rehabilitation, 2017). It is suggested that everyone in this research had a mild to moderate disability and would be EDSS ≤ 6.

Table 2.2 The Expanded Disability Scale

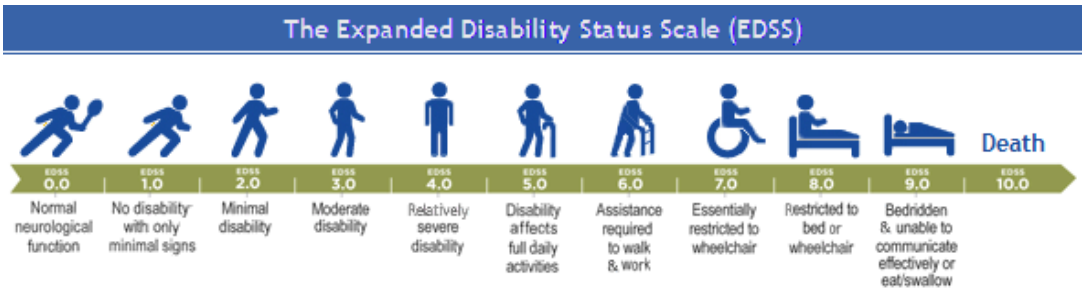


Table 2.2 Table showing the expanded disability scale. Retrieved from: http://multiple-sclerosis-research.blogspot.com/2014/12/clinicspeak-neda-at-7-years.html

A definition of PA and exercise was explained to the participants to help the flow of the interview. The aim was to keep the interview as open-ended as possible, but a list of prompts was used if necessary. Current engagement in PA and the barriers to participation were explored, and the perceived impact of exercise on QoL discussed.

Participants were asked to identify anything that acts as a barrier or facilitator to PA and their opinion on how the PA may impact on QoL (Appendix F). Interviews lasted no more than 45 minutes to ensure fatigue was minimised.

Interview question development

After the literature review was completed the initial question guide was modified. Learmonth and colleagues (2017) identified that pwMS want to receive exercise promotion from health-care providers with expertise in MS (i.e. neurologists). This led to a question being asked about whether the participants had themselves ever been recommended exercise by a MS health-care professional on diagnosis, later, or not at all (Appendix G).

Data Analysis

The interviews were audio-taped and then transcribed verbatim. Follow-up emails were made to participants if responses required further clarity. Data was analysed using thematic analysis procedure described by (Braun & Clarke, 2006). This was completed manually with codes and themes identified. Table 2.3 shows the phases of thematic analysis followed.

Table 2.3: Phases of thematic analysis (Braun & Clarke, 2006)

Phase	Process	Result
1 Familiarising yourself with your data:	Read and re-read each transcript. Make notes on first impressions.	Preliminary "start" codes and detailed notes.
2 Generating initial codes	Generate the initial codes by documenting where and how patterns occur. Label relevant words, phases, and sentences.	Comprehensive codes of how data answers research question
3 Searching for themes	Decide which codes are the most important. Combine codes into overarching themes that accurately depict the data. Some of the initial codes may be dropped – keep the codes which are important and create themes (categories).	List of themes for further analysis.
4 Reviewing themes	Look at how the themes support the data and the overarching theoretical perspective. Decide which themes are most relevant.	Recognition of how themes are patterned to tell an accurate story about the data.
5 Defining and naming themes	Label the themes, what is interesting about the themes, and describe the connection between them.	A comprehensive analysis of what the themes contribute to understanding the data.
6 Producing the report	Write the report. Describe the categories and how they are connected. Check description to ensure it is an accurate representation.	A description of the results.

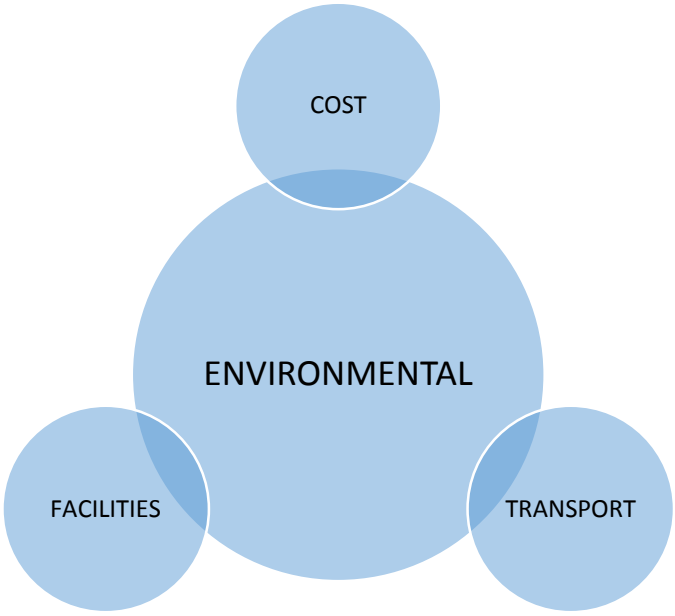
Table 2.3. Phases of thematic analysis. From *Using thematic analysis in psychology. Qualitative Research in Psychology,* Braun & Clarke, 2006.

Results

The results of this study include responses from 2 males and 10 females making the participant ratio 1:5. The majority of respondents were in the 50-59-year age bracket and all five of the MS types were covered (table 2.1), with the majority from the RRMS diagnosis. This is similar to the reported percentage diagnosis type in the MS population (Genetics Home Reference, 2017). Each of the 12 participants were randomly assigned a number from 1 to 12 (Table 2.1). Without exception, all the participants, even those with a low exercise level, commented on the positive effect of exercise participation and could name general health benefits. All participants achieved some level of PA (cleaning, taking the stairs, and walking), suggesting they were not classed as severely disabled. Only 66% did any planned exercise, with 40% of those meeting the recommended exercise guidelines (Appendix A, Chapter 1). Overall, five themes emerged from the analysis: *environmental, personal, knowledge, quality of life, and taking control.* Appendix I shows an example interview transcript.

1. Environmental – facilities available, transport, cost
2. Personal – motivation, time, physical limitations
3. Knowledge - beliefs about PA, recommendation, support of health care professional
4. Quality of life – fatigue, disability, psychological
5. Taking Control – management of disease, improving physical function.

Theme 1: Environmental



Availability of facilities was mentioned as barriers to participation, with the East Yorkshire "Grin & Tonic" activity session losing participants due to the MS Society unable to provide transport at the available time. Plow, Finlayson, Gunzler and Heinemann (2015) suggested that environmental barriers could be overcome with social support. The ability to offer this support through PA sessions can be associated with greater self-esteem and better QoL.

> *Missing an opportunity at this new Tuesday MS group, now they have built a group up could add in some exercise*. (Participant 4 SPMS)

> *Well yes…. people in those positions should give me more opportunity…. but I do have to blame myself - I lack the motivation – but would find it helpful if they came behind me to do more activities and pushed me.* (Participant 2 PPMS)

A barrier is that the exercise isn't local to me. (Participant 2 PPMS)

Participant 2 also mentioned about the cost of private classes as they weren't now subsidised by the council.

I know I don't do enough – if she did Pilates more local I would go twice a week – it used to be slightly subsidised when it was run by the council £4 but it's now £5. (Participant 2 PPMS)

Interestingly, participant 12, who has CIS (the first clinical presentation of the disease), would be interested in attended MS-specific exercise sessions and acknowledges the benefit of social support.

None have been offered. I would possibly be interested in attending, more to support and encourage others…. it may be more beneficial to attend a specific MS focussed session because of the shared experiences and understanding of others attending. There may be less pressure to 'keep up'…..ummm can go at own pace.

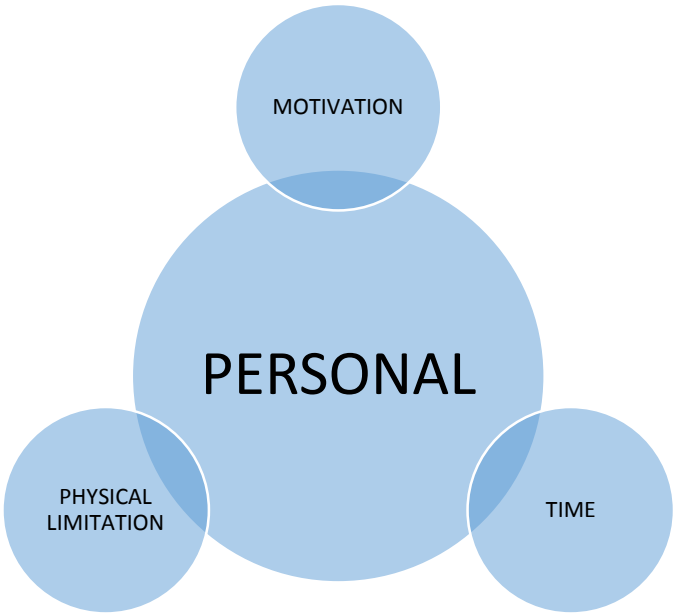
She also suggested that if exercise is of benefit it should be offered in hospitals before and after discharge.

If physical activity is recommended, could groups not be held in hospitals so people can see and try the sorts of things being recommended…. You know…. in a safe environment with the support of peers?

Optic neurosis and other MS disabilities may mean an individual is unable to drive therefore transport for this population becomes more important. Participant 2 had paid for his car to be modified to use hand control only, allowing him to remain independent and attend a weekly Pilates class. The environment must be

accessible to encourage exercise participation, as engaging in PA has been shown to produce positive effects on mental health (Sharma, Madaan, & Petty, 2006).

Theme 2: Personal



Three of the sample group were classed as achieving a high level of exercise; others, similar to the general population, found motivation and time as a limiting factor in their exercise participation.

> *It's just finding the time! You have to prioritise it and at the moment I don't prioritise exercise*. (Participant 3 RRMS)

Lack of motivation was partly due to the cuts in rehabilitation care:

> *I'm not getting the regular reviews like I used and not getting the stimulus to do exercise…..If I got more help yes I would do more – when I saw the physio regularly that was a good thing and motivated me*. (Participant 2)

Motivation gained from group participation has been mentioned in theme 1, but just having a "gym" buddy would help with the confidence to start attending a class.

I would like to do more yoga as I have found this beneficial to my MS in the past. I think if I had a friend to go with, this would motivate me to go regularly. And it needs to be local. (Participant 3 RRMS)

Plow, Finlayson, Gunzler and Heinemann (2015) found that a group of men achieved emotional well-being in an exercise class run by the MS society in their RCT. This supports the findings of Motl et al. (2011) who suggested that social support can boost motivation.

No adverse symptoms were reported by any of the participants due to exercise participation.

I do get tremors and my balance is worse and I get tired but they aren't really made worse by exercise. (Participant 5 SPMS)

Very little effect apart from the fatigue – my balance but that's not because the exercise is making it worse. (Participant 6 PPMS)

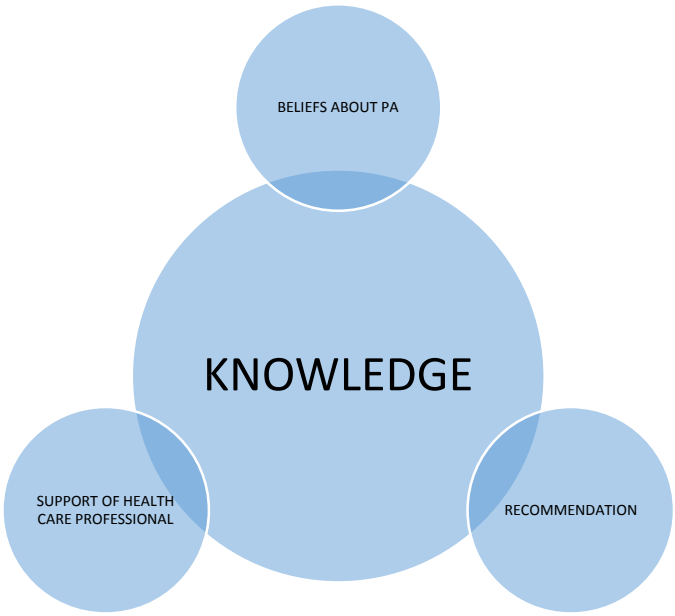
I listen to my body and can tell when I've over exerted myself – I may start to get numbness/loss co-ordination and then I know I need to rest. More often than not, I would say, I feel better for doing it (exercise) then not. (Participant 7 RRMS)

The National Institute for Health and Care Excellence (NICE, 2016) suggests that people with MS should be encouraged to exercise; they further conclude that PA is beneficial and does not have harmful effects on MS. One participant stated that her diagnosis had made her more active.

Having MS has probably made me more active than I would have been. I need to be doing something to help. (Participant 8 benign

This is in line with research by Motl (2014) where self-management of symptoms was a facilitator for behaviour change. Participant 8 was the only person to have received exercise advise on diagnosis. Recent research has found that behavioural interventions that are based on principles of social cognitive theory and delivered through a cost-effective dedicated web site achieved an increase in PA in pwMS (Motl, 2014; Sandroff, Klaren, Pilutti, 2014).

Theme 3: Knowledge



Many of the participants expressed the need for information and recommendation by a health professional to help them take steps into being more active.

> *I was told losing weight would help me have a better QoL with my MS and I lost the weight – I did that through diet though so I suppose if that made me do that because I was advised to, yes I suppose I would do PA if I had been told to*. (Participant 9 RRMS)

Participant 4 when asked about how much exercise she thought she should do:

> *…more than I do probably but not sure of what is actually recommended.*

She also went on to suggest that more guidance was required:

> *Not enough information on the benefits of ex to pwMS – you hear about being active but you don't get told how or given any recommendations….. I have another friend with MS who would really benefit from doing some PA but she just won't – she says she doesn't know how too, we did start trying to find her something on-line but there was hardly anything out there that was suitable for her.*

Participant 3 (RRMS) did feel that it was up to them to commit to exercise but some recommendation would help:

> *Erm To be honest, I think it is down to me to commit to it. A nudge from the MS nurse or whoever would help motivate me I suppose but I am aware that exercise is important so need to find a class and commit to going regularly.*

Other comments related to not knowing if exercise was of benefit for MS symptoms.

> *Yeah If I was told it would help my MS I would be more motivated to find the time – at the moment it's just the weight loss thing so I might go more before a summer holiday but if I was advised that it was going to help my MS in the long run yeah I would go the gym or do what they recommend.* (Participant 9 RRMS)

> *I think the MS nurse gave me a leaflet about exercise but didn't say if you do this every day it will help you or anything*. (Participant 11 RRMS)

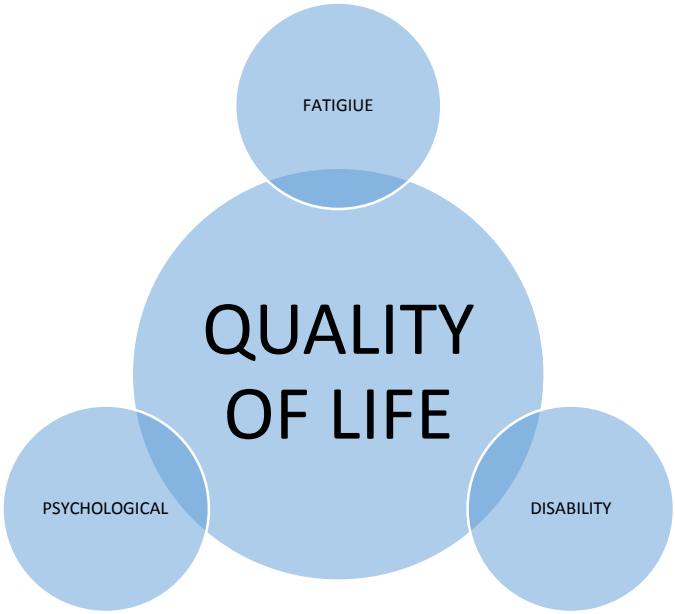
People with low levels of PA need more support from health professionals. This has been demonstrated more in men in study by Anens, Emtner, Zetterberg, & Hellström, (2014) who also found men reported a higher MSIS-29 score.

> *I know about the benefits - there probably isn't enough help to get someone start in exercise to help their MS, you know, who didn't do anything before That's the problem, motivating and making things available, I'm already motivated as I did PA before and have continued.* (Participant 10 RRMS)

Only one of the participants was advised exercise on diagnosis; five others were recommended to take part in exercise by the MS nurse or by a physiotherapist at a later date. These participants reported completing some amount of exercise. This is in line with the recent research by Learmonth and colleagues who found that advice from health-care providers may be very effective in changing a patient's exercise behaviour (Learmonth et al., 2017). Research on the general population has suggested that one in four people would be more active if advised by a GP or nurse, but many GPs in England (80%) are unfamiliar with the national PA guidelines (Chatterjee, Chapman, Brannan, & Varney, 2017).

> *No I haven't (been advised by a healthcare professional) they don't give you any lifestyle advise, just explain the drugs available to you and possible side effects of them.* (Participant 3 RRMS)

Theme 4: Quality of Life



The overall aim of this study was to assess the role of exercise on QoL in pwMS. The categories included were mainly psychological, fatigue, and muscular strength - which could have an impact on performance of everyday activities. Exercise may help reduce MS fatigue (Patti et al, 2003) but it also acts as a barrier to PA participation.

> *I'm sure it would help my fatigue, generally feeling fitter, keeping the weight off, stronger for life, and general well-being. It's just finding the time! You have to prioritise it and at the moment I don't prioritise exercise….. lack of sleep can bring on a relapse, that's my priority limiting my fatigue*. (Participant 3 RRMS)

Participant 6 described how she could do most things, but not for long. Her longest PA was for 20 minutes walking before needing to rest.

Can do 20 minutes unaided walk with someone and they catch me if I go - I push myself all the time…. I think that is the key to being active, keep pushing yourself, I would just sit and sleep all day otherwise.

Feeling stronger was a motivator to exercise. Two of the participants described how they believed they had a stronger core which helped them stop falls.

I would be worse if I didn't do Pilates – I can't prove it - but I'm stronger and it is helping my core. I have the feeling it is helpful ummm, I seem to be able to stop myself from falling, if I didn't do Pilates it would be worse. I think exercise is important. (Participant 2 PPMS)

It works the smaller muscles that you don't use by just going in the gym. I'm convinced it is helping me – just by keeping everything strong. (Participant 1 PPMS)

Being part of a team or having a competitive streak helped with motivating and general well-being of participants. This was especially prevalent at the East Yorkshire "Grin and Tonic" session (Appendix H – East Yorkshire Council Survey), where 100% of those surveyed felt that taking part in the activity made them feel less lonely or isolated.

I love it because I love sports, this is the sad thing, we do volley ball seated and love it…. I played volleyball when I was at school and college…. these sessions are such fun. (Participant 5 SPMS)

It is harder than you think actually but the main thing is it is a lot of fun (Participant 4 SPMS)

Exercise has been shown to improve QoL through general well-being and reducing depression (Motl & Gosney, 2008). And as a preventative strategy for reducing psychological stress.

> *It's the social - if you don't come to the coffee morning or Pilates you are not existing, you are not getting out*. (Participant 11 RRMS)

> *Yes it does (improve QoL) and it brightens you up as well, lifts your mood the social aspect.* (Participant 5 SPMS)

The neuroprotective impact of exercise and the slowing of structural degeneration of brain tissue is more difficult to research. A small scale RCT with 35 participants with RRMS did find that progressive resistance training seemed to induce a neuroprotective response when measured using MRI scans (Kjølhede et al., 2017) which could lead to slowing of disease progression and cognitive skills.

> *My MS would have been worse, absolutely, if I hadn't had exercised….*
> *Went swimming last week for the first time in ages and managed 10 lengths – it used to be my aim to get to 10 lengths – but I did it which must be because I'm generally stronger.* (Participant 4 SPMS)

> *Muscle control, when I was sitting I was sort like shrinking into a little shell almost, now I do a bit of exercise I'm sitting up better and when I go on the walker at the weekend I'm able walk a little more and a bit better but I'm errr well I said about a walker to them ages ago and they said no we don't do them so I've wasted two years of my life when I could have been walking and I feel so much better, mentally and physically. We do a quiz at the end of the session (Grin & Tonic) too, even that's fun.* (Participant 5 SPMS)

These findings suggest for improved QoL exercise advice for pwMS is warranted. This is the same as the conclusion of Jelinek and colleagues in a large cross-sectional study where diet and exercise were found to be associated with improved QoL (Jelinek et al, 2016).

Theme 5: Taking control

All 12 participants, even those who had a low level of exercise participation, spoke of the importance of PA to maintain function and take control of their condition. This was expressed by participant 1 who has PPMS:

> *You are told you have a progressive disease, there is no treatment for it and not likely to be in the near future. You need to take control somehow. I used to do it to be fitter, maybe compete in an event, I now do it because I believe it will help me stay active and hopefully slow down progression.*

Other participants believed that exercise participation was important to have the belief that you could be controlling the disease.

Ummm helps me believe I'm a being proactive (Participant 8 benign)

I've always been an active person, always, it's interesting I played netball then when I had children you get so busy don't you, but me and my husband have always done ballroom dancing – always try to be busy. Then when I came to York got in to the gym and exercise class – and couldn't imagine not doing it will always forever do classes, it helps with everything mentally and physically. Enjoy it – so makes me happy I would never not come to classes and the gym and my aim is get back to the level I was. (Participant 10 RRMS).

Really enjoy Pilates – and I wouldn't have been standing up if I hadn't been doing it all these years. My core is not bad for someone with my problem, it saves me really because I do potentially fall a lot but I can generally save myself because I'm stronger – it I do fall I've never really hurt myself and I think that's because I have strong bones. (Participant 4 SPMS).

Discussion

The present findings suggest that organised health interventions play a significant role in the promotion of PA and helping decrease social isolation. To help improve QoL for pwMS exercise and PA should be encouraged by a health professional early in the diagnosis. Medical care often dominates the services provided to pwMS, yet there are number of other activities that promote wellness which should be discussed with the patient. Exercise participation often comes at the expense of another activity to a greater extent than in the general population: everything takes longer for those with MS and fatigue is a major factor. The ultimate goal is to cure MS, but until a cure is found it is important to maintain QoL. It is fundamental that the client is the main focus when implementing interventions, so that any environmental barriers are minimised; transport provided and adapted facilities available. Inactivity leaves the MS population vulnerable to a range of secondary conditions and a reduced QoL.

Participants who achieved recommended guidelines were the ones who did so prior to diagnosis. Since diagnosis many had started Pilates classes; this was, however, their only weekly exercise involvement. This had either been recommended through seeing a physiotherapist or from completing their own research. Those who did take part in this type of exercise believed that their QoL would be reduced without it and they would not be as able to complete everyday tasks as easily. This qualitative research did highlight that a greater uptake of activity would be achieved if recommended by the neurologist. Participants want to know which type of exercise is most beneficial for them and how to access these classes. Only one participant

had been recommended exercise at disease onset when she was diagnosed in New Zealand. She was recommended yoga, which she still practices 15 years later.

Multiple sclerosis is not yet fully understood and an active management plan, including PA, to improve health and QoL is important. As early as 1948 the World Health Organisation described health as a "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948). It is important to have a multi-faceted wellness programme to make the most of physical, emotional, social, and spiritual health. Current research is now shifting to the idea that myelin damage can be reversed (remyelination) during the early stages of MS (Queen's University, Belfast, 2017). The neuroprotective effect of exercise is certainly plausible but PA benefits in the broader sense have been shown in this study to have a positive effect.

There are several strengths to this study, including the full range of MS types achieved and the one-to-one person interviews, which allowed a rapport to be built with participants. Important areas in evolving research about pwMS was also addressed through questioning leading to implications in future clinical practice. The study has limitations and, as with qualitative study, it is unknown if these findings are general to most of the MS community. As the participants were self-selected, after they had expressed an interest in taking part, there is likely to be a bias towards pwMS who understand the importance of PA, even if they don't take part in any planned exercise. Completing a focus group with participants who were unmotivated to engage in PA could have helped reduce any bias.

Conclusion

Physical wellness is a facilitator for QoL. Despite this evidence, PA recommendation by health professionals is limited. This study showed that pwMS were limited in their knowledge on how certain aspects of their disease could be modified through PA participation. They were also unaware of any recommended PA guidelines for pwMS. The choice of exercise will depend on one's lifestyle, physical functioning, and the availability of suitable facilities. This project has highlighted similar results to those already published in that pwMS engage in low levels of PA compared to nondiseased populations (Motl, McAuley & Snook, 2005). Lack of exercise participation has, in part, been blamed on the historical view of health professionals that pwMS should rest (McAuley et al., 2007). Neurologists and other health care professionals have a responsibility to promote PA engagement. This inactivity contributes to the onset of: secondary conditions, reduced physical functioning, and social isolation. This research has highlighted important aspects in PA participation for pwMS to improve QoL and resilience:

- Health care professionals should recommend PA and exercise participation at the onset of the disease.
- People with MS should be advised of recommended exercise guidelines.
- Health promotion interventions with transport provided should be made available.
- Barriers to participation include: lack of knowledge, lack of motivation, transport issues, disability, and physical fatigue - The majority of these barriers can be eliminated through planned interventions and guidance from a health professional.

Good nutrition and physical fitness should be encouraged for people with MS by their clinical providers. This is especially important for those diagnosed with the progressive form of the disease at the onset, where there is currently no effective disease modifying treatment (Ontaneda, Fox & Chataway, 2015). The presence of "Hope" appears to play an important role in helping individuals with PPMS maintain emotional

wellness and improves QoL. The burden of this disease on the individual, and society is enormous, with the cost to the economy estimated at £4 billion each year (MS Society, 2017). It is time to make lifestyle improvements as important as disease modifying drugs in the rehabilitation of pwMS. The funding for many of the clinical trial studies in MS (and other diseases) is from drug companies who will be hoping to supply a profitmaking product. Lifestyle alternative treatments are limited through their lack of funding and are therefore mainly small scale, but that does not mean they should be ignored.

Future Research

Clinicians can influence PA engagement for those living with MS. More effective promotion of exercise by the neurologists and MS nurses is needed and these strategies should then be evaluated. Taking control of their disease progression was an important factor for respondents. Future strategies should be developed where exercise technique and benefits are taught before leaving hospital, with clear information about how the continuation of these exercises can have a positive effect on their MS. Evaluating the effectiveness of this simple step of promotion of PA by a clinician at disease onset, prior to advancement of the disease, should be completed through a cohort study. Appropriate outcome measures of the six-minute walk test, and the MSIS-29 have been recommended by Paul et al, (2014) for all exercise-based research studies. These are cost effective and can be used in large studies. For further evidence RCT's can incorporate MRI brain scans to observe any positive effects on the brain structure and to see any areas of inflammation.

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